

# **TIIAP FY 1999**

## **Project Narrative**

Association of Kansas Hospices

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Health

Wichita, Kansas

## Telehospice: A Bistate Proposal to Improve End-of-Life Care

### **I. PROJECT PURPOSE**

**The Problem:** In spite of rapid medical advancements and great changes in the health care system, one thing has remained constant: *everyone eventually will die*. Startling results from recent studies reveal that many people die in great pain, suffering at the hands of well-intended, but sometimes unskilled providers.<sup>1,2</sup> In addition, while 9 of 10 Americans prefer to die at home in the company of loved ones, more than 85% actually die in an institutional setting, either the hospital or extended care facility.<sup>3</sup> Clearly we are challenged to assure a humane and compassionate end-of-life experience for the dying. Hospice was first introduced in the 1970's, using a non-interventional emphasis, for care of the dying in the home setting. Family members are integral participants in the process as they provide day-to-day care, often stepping into a caregiver role that is entirely foreign. For this reason, the hospice team provides counseling and support to family members as well patients. While there has been growth in the number of hospices in the last twenty years, only 15% of the dying in this country access this specialized service for many reasons.<sup>4</sup> For rural populations hospice expertise may not exist locally.<sup>5</sup> Also, some experience their illness in isolation, without the support of family or friends serving in the caregiver role.<sup>6</sup> Some minority populations go underserved even when located in an urban setting.<sup>7</sup> For some cost may prohibit access to hospice professionals.<sup>8</sup> While hospice care may be available, some physicians fail to refer patients--clearly provider education is essential to assure quality end-of-life care.<sup>9</sup>

**The Solution:** Telemedicine has the potential to address barriers to quality end-of-life care with the provision of clinical and educational services. Hospice care may be delivered directly into a patient's home via telemedicine (telehospice) for clients in underserved rural and urban sites and for those with limited caregiver support.<sup>10</sup> In addition, educational programs may be offered via interactive video to teach principles of end-of-life-care to healthcare providers.

Two large hospice organizations located in Kansas and Michigan will launch telehospice projects using POTS (plain old telephone service) technology to reach rural underserved populations and those urban groups that have gone without services. The hospices were chosen based upon their statewide presence, reputations for high-quality services, and enthusiasm for trying an innovative solution for access problems their client's face. Telemedicine units will be placed at the hospice office base stations and the homes of nurse providers for on call use. At any given time, forty clients from rural and urban homes in each state will have units. The project will be conducted over two years, with the implementation set for the fall of 1999, with ongoing evaluation through the duration of funding.

Home-based telemedicine units will be utilized to link hospice care teams (nurses, social workers, and chaplains) with hospice clients and family caregivers. Tele-nursing visits will be conducted on a weekly basis at a minimum, with frequency of calls determined by individual patient needs. Pain and symptom assessments and psychospiritual evaluations will also be conducted electronically. Social workers will connect for initial intake assessments, counseling of patients and for support of caregivers prior to death and in the bereavement period.

Education of physicians and nurses in end-of-life care is essential if we are to improve care for the dying.<sup>1,11,12</sup> In Kansas, continuing medical education courses have been offered to rural sites via interactive video since 1991.<sup>13</sup> Recently, a comprehensive curriculum has been developed to train physicians in care of the dying (Educating Physicians in End of life Care—EPEC). In Kansas, during the first year, this course will be offered three times via interactive

video. Each course will consist of two-hour lectures delivered weekly for a total of eight weeks. Each lecture will be set up as a multipoint event that will reach physicians in six communities. Continuing medical education credits will be given for participation (16 contact hours per course). Also, during the first year of the grant, an education network for the EPEC curriculum will be developed in Michigan. During the second year of the project, the EPEC course will be offered to sites jointly in Kansas and Michigan via interactive video every four months.

**Measurable Outcomes:** The primary goal of this project is to improve care through the dying process. To assess whether the goal has been met, the researchers will evaluate access of services, medical outcomes and costs.

**Access and Delivery.** Telemedicine has the potential to allow access to hospice care electronically, connecting clients and providers that are separated either geographically (rural) or functionally (urban). For the rural population, even when hospice is needed, the small patient base may not justify the existence of local providers. Thus, distance separates clients and providers. Access issues also exist for urban populations that are unable to receive hospice care due to limited financial resources, inadequate education, lack of family support, or cultural factors. This project will monitor utilization of services and compare data collected before and during the study period. In addition, an analysis of the optimal delivery including roles and responsibilities for hospice providers will be conducted. Timeliness of care will also be analyzed, comparing immediate teleconsultation with traditional in-person visits.

**Medical Outcomes.** A major focus of study will be quality of care and medical outcomes. Assessing a patient's level of pain is one tool used in hospice care to determine whether a dying patient's medical needs are being met. Pain evaluations will be conducted looking at diagnostic accuracy and timeliness, comparing traditional with telemedical assessments. Standard pain assessment tools, previously validated, will be adapted for telemedicine evaluations.<sup>14</sup> Patient and caregiver satisfaction and perceptions of quality of care received via telemedicine will also be studied.

**Cost.** Although improved access to end-of-life care is the primary goal of this project, secondary goals include more timely evaluation of clients, enhanced care resulting from more frequent (electronic) visits, and reduction of costs. Since the primary payer for hospice is through a Medicare capitated fee system, telemedicine offers real potential for cost reduction by decreasing travel time and expenses related to in-person visits. Detailed cost data for home telemedicine are lacking.<sup>15</sup> A cost-measurement analysis will be performed including a detailed accounting of equipment expenditures, client and caregiver costs, and personnel time and expenses. These data will be compared with medical outcomes to generate a true cost-effectiveness evaluation.

## **II. EVALUATION**

**Evaluation Plan:** The strength of this telemedicine proposal is its focus on an evaluation plan that will answer vital questions far beyond the simple feasibility of this project. In order to provide information that can be utilized for future telehospice or telehomecare projects, the evaluators seek to measure clinical efficacy and outcomes, procedures and resources involved in establishing and delivering end-of-life care to the homes of patients, and track expenses to analyze the cost effectiveness of this service. Please see Appendix C for a timeline that displays the ongoing and longitudinal nature of this research.

### **Evaluation Questions:**

#### **Evaluation Question 1: Access Issues**

1a. What is the relative percentage of people receiving telehospice care who are in underserved groups (rural, urban, minority) compared to those receiving traditional hospice care?

1b. What was the utilization of hospice services before and during the telehospice study, for those using the technology and those receiving traditional care?

Evaluation Question 2: Clinical Efficacy and Outcomes

2a. Can an accurate pain assessment be performed via telemedicine compared to in-person?

2b. What is range of hospice services can be delivered via telemedicine? What hospice services *must be* rendered in person?

Evaluation Question 3: Cost Issues

3a. What is the average cost to provide hospice services to the home using telemedicine compared to the average cost using more traditional delivery methods?

3b. What potential savings are there (1) for the healthcare system and (2) for clients/ caregivers?

Evaluation Question 4: Delivery of Telehospice Services

4a. What procedures/protocol are necessary to provide telehospice services? How does the provision of hospice service via telemedicine differ from the provision of hospice service in person? 4b. How does the use of telemedicine impact the provider-patient interaction (e.g., what subjects are discussed via telemedicine? what types of nonverbal communication are utilized during visits?) 4c. Are patients, caregivers and healthcare providers satisfied with the use of telemedicine to deliver end-of-life services directly into the home?

Evaluation Question 5: Education Program Are health providers satisfied with the quality and content of the ITV continuing education received during this project?

Evaluation Strategies: Both quantitative (surveys, health assessments, archival data) and qualitative (in-depth interviews, observation, focus groups) methodologies will be employed to address the three research questions. Study subjects will include hospice providers (nurses, social workers, chaplains, physicians), patients, and caregivers. Data from this telemedicine study will be compared longitudinally and cross sectionally to control data accessed from charts of those that receive traditional hospice care. The technology will be assessed in relation to its ease of use, ubiquity, reliability, and cost benefit.

Data Collection and Analyses: The methodology for data collection and analyses will vary for each of the research themes.

*Evaluation Question 1. Access Issues:* Logs will be kept to track all patients that are offered telehospice services to determine the frequency of acceptance or refusal of the service. Utilization will be monitored checking frequency of visits, timeliness of care and appropriateness of telemedicine visits.

*Evaluation Question 2. Clinical efficacy and outcomes:* A standard pain assessment tool, the Brief Pain Inventory, will be used to survey pain history, location and quality will be administered. This tool will allow investigators to assign a numerical score to each pain assessment whether via telemedicine or in-person. Each televideo session will be recorded (with patient consent) for analysis by the team of evaluators (hospice physician, psychologist). Means testing will be conducted between pain assessment survey results to determine if there is a significant difference between values obtained via telemedicine when compared to in-person visits. Second, archival data will be pulled from patient charts for analysis of services provided in person and for comparison to services rendered via telemedicine.

*Evaluation Question3: Cost Issues:* The cost research question will be addressed by utilizing the costing frame previously developed for KUMC telemedicine cost studies.<sup>16,17</sup> Estimates of costs obtained from this frame will be combined with data collected from participating families and patients via interviews as well as existing claims data from patient charts.

*Evaluation Question 4: Delivery of telehospice services:* In-depth interviews will be conducted with hospice organization staff members to document protocol, procedures, and resources needed to provide telehospice care as well as traditional onsite hospice services. In-depth interviews will also be utilized to gather data from providers, patients and caregivers related to satisfaction and acceptance of telehospice services and education. Thematic content analysis will be conducted on all open-ended interview data. Interview questions that ask the subject to rate a question on a Likert scale will be analyzed via descriptive statistics. Key project hospice staff will also be required to maintain a logbook documenting progress, challenges and obstacles of project during implementation, planning and maintenance. This data will be coded using thematic content analytic procedures. Randomly selected telehospice visits will be videotaped with patient permission to provide data on the communicative aspects of a telehospice visit. Verbal communication will be coded by theme and nonverbal behaviors will be counted by occurrence.

*Evaluation Question 5: Educational program.* Pre- and post-test clinical assessment exams will be developed and administered as part of the program. In addition, satisfaction evaluation tools for course participants will be administered.

Evaluators: A team of evaluators has been assembled with expertise in each of the research areas: a clinical oncologist with an extensive background in providing hospice services (Gary Doolittle, M.D.); a communication professor with a research background in the analysis of the delivery of health services (Pamela Whitten, Ph.D.); a psychologist specializing in cancer pain assessment (Robert Twillman, Ph.D.); a communication specialist with an interest in provider/patient interaction (David Cook, Ph.D.); and a health economist specializing in cost analyses of innovative medical services (Arthur Williams, Ph.D.). Each of these evaluators has focused his/her research expertise in telemedicine. A description of the research team and biosketches are available in Appendix D and Appendix E.

Budgeting of resources and staffing for evaluation: The project includes research expertise for each of the research questions outlined above. The two Principal investigators, who have extensive experience in telemedicine, will be responsible for ongoing management of the project in each respective state as well as coordination of the evaluation components. Experience has taught the co-PI's of this project that to adequately conduct an ambitious evaluation plan, support is required for data collection and administrative functions. For this reason, a .5FTE doctoral student and .25FTE undergraduate student have been budgeted for each state. In addition, a .5FTE nurse coordinator has been budgeted. A part of his/her responsibility will be to assist in data-collection coordination at his/her respective hospice.

### **III: PROJECT SIGNIFICANCE**

Utilizing telemedicine technologies in the home is a new, growing trend in the United States.<sup>18</sup> The majority of these projects target a particular diagnosis or service area. This Telehospice project will make an important contribution to the field of home health by advancing the level of knowledge in four significant ways. First, it will provide important lessons about the ubiquity, reliability and timeliness of telecommunication technologies to deliver critical medical services directly into patients' homes. Second, it will tell us whether telemedicine can positively affect the home health field that is currently in disarray due to its inability to cost-effectively reach many patients needing its services. Third, it will demonstrate whether telemedicine can be used to overcome barriers to access in urban and rural areas. Finally, it will provide data, which will enable future providers throughout the country to easily incorporate telehospice services into their service mix.

Traditionally, hospice care is praised for its focus on emotional, psychological, spiritual, and social support. Developing interpersonal relationships is a salient part of this approach. This project examines the utility of technology as a communication tool in a highly interpersonal environment.

By utilizing two states, Kansas and Michigan, this project offers practitioners and researchers an opportunity to assess the quality of end-of-life from a population base larger than any previously conducted study. The highly rural nature of Kansas in comparison with the urban areas of Michigan offers an environment for comparative inquiry. Comparisons may further be made in regard to the demographic make-up of these states. Hospice of Michigan (HOM) serves diverse Latino, Arab, and African American minority populations. Hospice Inc. in Kansas extends statewide services to a population base of only 8% minorities. Importantly, both organizations have extensive networks that reach both rural and urban communities.

Finally, Tele-Hospice utilizes a low bandwidth solution to meet project objectives. This strategy will increase access to a broader population and decrease costs. Most importantly, through documentation and rigorous evaluation, this project will provide hospices nationwide with a template that will enable them to easily launch their own telehospice project.

#### **IV: PROJECT FEASIBILITY**

**Technical Approach:** A team of physicians, nurses, technicians and administrators was assembled to evaluate the options. It was vital to define the technical constraints of providing this service into the homes of patients. The first constraint involves the short time frame in which providers have to install and initiate a telehospice service in a patient's home. Patients requiring crucial end-of-life services have a matter of months and sometime weeks left of life. They simply cannot wait 2-3 weeks for a digital ISDN line to be installed. For this reason, this project required an extant ubiquitous telecommunication infrastructure. Because many of the patients requiring telehospice services live in rural areas, POTS (Plain Old Telephone System) was the only real option. As DSL (Digital Subscriber Line) technologies become disseminated, we hope to enhance this project by using xDSL on existing copper wire into the home. At this point, however, we must start with a system that can run into anyone's home via twisted pair wire. The second constraint was the need of interactivity, which hospice providers determined was necessary for adequate care and communication. Because caregivers and patients would be operating the equipment after installation by a hospice nurse, we needed something easy to use. And because these units needed to be located by patients who are often located in family quarters with constrained space, we needed equipment that did not tax this space. For this reason, we selected an interactive video system that operates through an analog phone line and an ITV unit. The providers, who need a larger view of the patient, will be able to receive the image in their office through a traditional (NTSC) television monitor and analog phone line. The brand selected is available off the shelf (ViaTV, 8X8, Santa Clara, CA). Installation and usability were tested in a pilot study by laypersons and hospice personnel. Participants, when asked to use this equipment with no directions other than a user guide, had little trouble installing and operating the telemedicine equipment.<sup>19</sup>

This technical solution exhibits strong *interoperability* as it is based on H.324 standards. Because of its relatively low cost and "plug and play" status, this equipment can easily be utilized by other community organizations also involved in the provision of end-of-life services. After extensive research, this was found to be the most reasonable, low cost option, with no other *technical alternative* identified to meet telehospice objectives. This project is taking advantage of an existing infrastructure and products in order to save valuable time required for the actual

provision of a hospice services. The potential for enhanced *scalability* is quite strong for this project. Because of the use of an existing telecommunication infrastructure and a product that can be purchased off the shelf, the number of telehospice recipients and regions providing this type of care can grow quickly if the results of evaluation indicate this is appropriate. *System maintenance* is not complex for this project and will be conducted by a single technician, available to hospice personnel in both states. This task will require inventory management and allocation.

Delivery of continuing education for hospice providers will be done through an existing network of interactive video equipment existing in both Kansas and Michigan. Events will be transmitted at 384 Kbps through a multipoint control unit located in Kansas. This way, we can easily accommodate up to 12 sites at any given time. All equipment operates at H.320 standards meaning that all sites, even with different equipment, will be able to communicate with all other sites.

**Applicant Qualifications:** Each of the project investigators has extensive experience in the administration and evaluation of telemedicine projects. More importantly, the participating hospice organizations in both Kansas and Michigan have national reputations for groundbreaking and innovative services for their hospice patients. The combination of PI's with the experience to successfully launch a telemedicine program, hospice organizations dedicated to providing high quality end-of-life care, and an evaluation team with the skills required to address vital questions about this project, indicates that this project is clearly comprised of qualified and committed participants. Please refer to Appendix F for more detail on the applicant's qualifications.

**Budget, Implementation Schedule and Timeline:** The proposed budget includes equipment, personnel (service and evaluation), overhead and travel expenses. Matching is through provision of matching personnel costs and equipment. In addition, the costs of hospice services will not be paid for by the grant but by other payers. Nevertheless, these are part of the costs of the program but no piece will be born by the NTIA. The implementation schedule (See Appendix C) outlines salient activities and project milestones across the two-year period. Continual data collection will occur throughout the implementation schedule. Monthly meetings between the project partners will be scheduled to continually assess the progress of the project.

**Sustainability:** A strength of this project is the fact that it is building a service into an existing health infrastructure of providers and payers. The two hospice organizations already exist in full form equipped with all clinical and administrative expertise for end-of-life care. The challenge is to enable patients to access this expertise in cost-effective ways. This challenge is addressed by this telemedicine project. In addition to the existing health delivery system, this project is sustainable because of an existing reimbursement structure. Hospice care is primarily reimbursed in both states on a *per diem* basis regardless of how frequently or through what modality it is delivered. While many telemedicine programs attempt to add a new service that must invent a reimbursement schema, this project is being placed within an existing service and payment infrastructure.

#### **V: COMMUNITY INVOLVEMENT**

This project has a diverse supporting cast with strong relationships throughout both states. In 1982, the Association of Kansas Hospices (AKH) was initiated with a goal of identifying major barriers to quality care at the end of life. In line with this goal, the AKH is submitting this grant application to improve end-of-life care for all citizens. The organization has extensive relationships throughout Kansas, including partnerships within the state government, state universities, prominent non-profit agencies and statewide associations

including the Kansas Medical Society, the Kansas State Nurses Association and the Kansas Cancer Pain Initiative. In addition, AKH is gaining national prominence for its role in hospice advocacy and will effectively coordinate a bistate project.

Hospice Inc is the largest hospice organization in Kansas serving 27 counties throughout the state. Currently, it serves approximately 180 patients per day and more than 1,000 families per year. The staff includes 130 full-time and 300 volunteer caregivers. Relationships include service contracts with more than 80 nursing homes and 35 hospitals. The Hospice of Michigan is the nation's largest non-profit hospice by area and number served. Currently, it serves 900 patients and their families per day equating to 6,000 per year. The staff includes 23 physicians, 949 full and part time employees and 900 volunteers.

Several project characteristics provide a foundation that will enhance community involvement that has already begun for this project. First, the extensive community involvement of these organizations allows services to be provided to a wide range of rural and urban communities, with diverse ethnic and cultural demographics. Second, the ubiquitous bandwidth solution (POTS) will allow services to be provided to anyone in these groups with a telephone line in their home. Third, experienced translators that are already on staff will be used to alleviate language barriers. Fourth, project coordinators are experienced at marketing and coordinating activities to the targeted underserved populations. Providers at the community level have been involved in the conception of this plan and will play an active role in the planning and dissemination of this project. Space limitations prohibit inclusion of all the letters of support offered for this project, however Appendix H provides a sampling demonstrating involvement and commitment at the community level.

#### **VI: REDUCING DISPARITIES**

Service and research focusing on end-of-life care has traditionally been neglected. The fact that the American Medical Association did not recognize "hospice care" as a medical discipline until 1995 strongly highlights this fact. Philosophically, dying patients are a group that have had limited access to benefits, information and even a high standard of care. Technological advances in North American society have resulted in a tendency to "aggressively" prolong life at all costs. The result is a "death denying" society that focuses little resources on end-of-life care. This project focuses on an underserved population in great need of services.

**Access/Cost Issues:** Access to services is a significant problem in end-of-life care. For example, in 1994, the National Hospice Organization reported that many of America's terminally ill have little or no access to hospice care (NHO, 1994). In part, this is due to a growing elderly, Medicare-eligible population. In 1982, Congress enacted legislation that created a Medicare hospice program to provide Medicare coverage for the terminally ill with a life expectancy of six months or less.<sup>20</sup> This was the first capitated reimbursement model in the United States, in which a per diem fee was paid for comprehensive care. As a result, Medicare hospice participation grew at a dramatic rate with the total number of hospices increasing 70-fold.<sup>21</sup> Unfortunately, the number of clients served has leveled off in the last five years for reasons that are not clear. The present reimbursement model presents particular challenges when caring for rural clients. Most rural hospice care is delivered by urban providers, requiring a significant amount of costly travel. Telemedicine offers an inexpensive way to conduct a visit, providing quality care but eliminating the travel time and expense.

**Minority Groups:** There is disparate utilization of hospice services by minority groups. An NHO study found of those receiving hospice, 85% were whites compared to 9% African-Americans, 3% Hispanics and 3% classified as "others".<sup>22</sup> One part of this study has been

designed to formally study hospice access by minority populations. One of the participating Hospice of Michigan sites, the southeastern division including Wayne County, possesses a unique demographic makeup. Of a total population of 850,000, forty percent is African American, with 3% Hispanics, and 1% Asians. In addition, there are over 350,000 Muslims in this region. Also, just west of Detroit in Dearborn, 30,000 Arab Americans reside. During 1998, over 40% of the patients served by the southeastern division were African American with less than 1% Hispanic, Asian or Arab. With the implementation of the telehospice program, and with the support of interpreters, HOM may achieve greater access to these non-English speaking urban populations.

**Bi-State Population:** Kansas and Michigan do not have adequate services for care at the end of life. In 1997 fewer than 20% of eligible Kansans received hospice care. In Michigan, only 15% of the dying receive hospice services. These numbers document a major strength of this grant application - its ability to address a vast underserved population from two unique regions. By utilizing two states, Kansas and Michigan, a diverse underserved population will be assessed. Importantly, the unique nature of these states offers a novel view for comparative inquiry. According to the federal figures, Michigan is the eighth largest state by population with 9,295,297 residents. It is almost four times larger than Kansas, which is the 32<sup>nd</sup> largest state with 2,594,840 people.<sup>23</sup> Michigan has an urban-rural population ratio of almost 5 to 1. For example, the northern division of Hospice of Michigan serves 21 counties. The area is predominately rural, and from east to west covers 150 miles. The telehospice program provides an opportunity to increase access to areas that are underserved due to geographic location.

In contrast, Kansas has a more evenly distributed population base with 1,452,862 urban and 1,141,978 rural residents.<sup>24</sup> The difference in the urban-rural and ethnic mixes of these two states has important policy and resource allocation implications, important for any study looking for generalizable solutions.

## **VII: DOCUMENTATION AND DISSEMINATION**

**Documentation Plan:** Documentation for this project began in 1997 when the technical feasibility project was conducted in Kansas City, MO.<sup>25,26</sup> This feasibility project demonstrated that it is possible to install POTS equipment into hospice patient homes in a timely manner. The documentation plan for this project includes a project log to be maintained by the nurse coordinator in each state; information formally charted in patients' records; quarterly reports summarizing project status, achievements and obstacles; and monthly project meetings which will be audiotaped. In addition, variables for a database are currently being identified in partnership with the Kansas and Michigan hospice organizations. The database will be created and maintained by doctoral research assistants.

**Information Dissemination Plan:** Academic papers will be submitted for publication documenting the findings from each of the evaluation themes included in this project. In addition, research findings and project experiences will be presented at academic and trade conferences by the evaluators and hospice providers. A handbook on initiating and managing a telehospice program will be created and made available over the Internet for any parties interested in launching a similar project. Finally, organizations interested in launching similar projects will be invited to Kansas and/or Michigan to observe this project and meet with key personnel.